Trajectories of the Transition Readiness Assessment Questionnaire Among Youth With Inflammatory Bowel Disease

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Objective: The objective of this study was to describe in detail the trends of the Transition Readiness Assessment Questionnaire (TRAQ-20) with respect to patient age and gender among a cohort of 655 youth with inflammatory bowel disease (IBD) to enhance the tool’s utility in clinical and research settings.

Materials and Methods: All participants in the Crohn’s and Colitis Foundation’s IBD Partners and IBD Partners Kids and Teens Cohorts ages 12 to 21 who completed the TRAQ-20 at least once were included. We computed centile scores for the TRAQ-20 and applied Kernel regression to generate curves. We computed mean scores for each TRAQ-20 domain by age for the overall cohort and stratified by gender.

Results: TRAQ-20 scores generally increase with age. Males have a steeper trajectory from ages 17 to 19 compared with females. By age 21, median overall TRAQ-20 scores for women and men were 4.4 and 4.7, respectively. The “Talking with Providers” domain of the TRAQ-20 had high scores throughout the age range of the cohort, while others had lower scores in younger ages and higher scores in older ages. All TRAQ-20 domains had mean scores of 4 or greater (out of a possible 5) among 21-year-olds.

Conclusions: TRAQ-20 scores increase with age. The rate of increase varies by gender. Rates of increase also differ across domains. The use of transition readiness growth curves can help providers and researchers identify patients who are not achieving expected levels of transition readiness and determine the level of transition readiness that a patient much achieve before transfer to adult care.

Key Words: transition to adult care, transition readiness, inflammatory bowel disease

The transition from pediatric to adult care is defined as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.” Approximately 25% of patients with inflammatory bowel disease (IBD) are diagnosed as children or adolescents, and these patients are at high risk of adverse health outcomes without adequate preparation and support during their transition to adult care.

National guidelines regarding transitional care emphasize the importance of measuring and tracking an adolescent’s readiness to transition to adult-centered care. The Transition Readiness Assessment Questionnaire (TRAQ-20) is a questionnaire designed to provide a self-report of an adolescent’s transition readiness. It has been shown to have good internal reliability and criterion validity in youth with chronic conditions ages 14 to 26, though it has not been validated in youth with IBD specifically. It has been used extensively in research settings including in studies involving youth down to age 12 years and in studies focused on youth with IBD. Its use in the clinical setting has been limited by the lack of a clear association between TRAQ-20 scores and health outcomes, and therefore a lack of a clear score-based indication for when a young person can be deemed adequately prepared to transfer to adult-centered health care.

Understanding the trends in the TRAQ-20 score as adolescents get older and take on more responsibility for their care can serve a number of uses. Just as growth curves for height and weight can help providers identify children whose growth may be faltering, similar curves for the TRAQ-20 may identify adolescent patients who may need additional transition preparation and support before their transfer to adult care. Such curves can also identify adequate versus inadequate increase in TRAQ-20 scores as patients grow older. Description of such trends will also provide concrete evidence to inform future benchmarking of the TRAQ-20 and its proper use in clinical and research settings.
settings, such as when to target education around particular self-management skills that contribute to readiness to transition to adult care. With that in mind, our research aim was to analyze trends in TRAQ-20 scores with respect to patient age and gender in a large sample of adolescents and young adults with IBD to generate graphical displays of these trends and to provide curves for the TRAQ-20 score with respect to age and gender that can be used in a similar manner to growth curves.

MATERIALS AND METHODS

All data for this study were obtained from IBD Partners and IBD Partners Kids and Teens, 2 parallel web-based cohorts developed and maintained by the Crohn’s and Colitis Foundation, a nonprofit organization that funds, publishes, and advocates for IBD research and provides support to IBD patients. Patients with self-identified IBD (or patients and their parents in the case of the Kids and Teens cohort) are invited to join these cohorts, which then allows participants to access the foundation’s educational resources, receive research updates, and participate in research surveys every 6 months. In addition to providing demographic information, disease and treatment characteristics, and patient-reported outcomes, participants age 12 to 21 completed the TRAQ-20 to assess transition readiness.

As previously mentioned, the TRAQ-20 is a validated questionnaire that provides a patient’s self-report of their transition readiness. It has 5 domains: “Managing medications,” “Talking with Providers,” “Appointment Keeping,” “Tracking Health Issues,” and “Managing Daily Activities.” The TRAQ-20 uses a 5-point ordinal scale response scale for questions with a range from 1 to 5, with higher scores representing greater levels of transition readiness. Scores are calculated for the overall score and for each domain. For this study, we report the overall score as an average of the 20 items in the total measure and the domains as an average of the items that contribute to each domain’s score, meaning that total scores and domain scores could range from 1 to 5.

Recruitment and Eligibility

The Crohn’s and Colitis Foundation recruited participants for the IBD Partners and IBD Partners Kids and Teens cohorts through their Web site, e-mail rosters, social media outlets, word-of-mouth at foundational educational and fundraising events, and other promotional efforts. The foundation continues to recruit new members to the cohorts. For the present analyses, we analyzed data collected through February 1, 2021.

To be included in this analysis, participants had to complete the TRAQ-20 at least once since they enrolled in the cohort. If a participant had completed the TRAQ-20 more than once, all instances at least 5 months apart were included.

Analysis

We calculated descriptive statistics for the eligible population. We then tabulated the distribution of TRAQ-20 scores by age to identify the 10th, 25th, 50th, 75th, and 90th percentile for each age group, both in the overall cohort and in analyses stratified by gender. Based on these results, we then applied the Kernel regression technique to generate curves for each percentile across age groups stratified by gender. Finally, we calculated the mean scores for each domain of the TRAQ-20 for each age group in the overall cohort and stratified by gender. Statistical analyses were performed using SAS 9.4 (SAS Institute Inc., Cary, NC).

| TABLE 1. Patients’ Demographic Information |
| Characteristics | n (%) |
| Total number of patients | 655 |
| Age [mean (SD)] | 15.76 (2.71) |
| Gender | 291 (44.4) |
| Race | 6 (0.9) |
| Hispanic | 41 (6.2) |
| Type of IBD | 10.87 (3.66) |
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Ethical Considerations

This study has been approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.

RESULTS

Baseline Characteristics

A total of 655 participants met our inclusion criteria (Table 1). Slightly over half (55.6%) were female, and most (88.4%) were white. Most (75.3%) had Crohn’s disease. The mean age at the time completing the TRAQ-20 was 15.76 ± 2.71 years and the mean age at the time of IBD diagnosis was 10.87 ± 3.66 years. Most participants completed the TRAQ-20 once (61.4%) or twice (18.8%).

TRAQ-20 Score and Age

Figure 1 shows the centile curves with respect to age for males and females, respectively. As expected, TRAQ-20 scores were generally higher with increasing age. Males had an apparent steep gain in TRAQ-20 scores from ages 17 to 19, while females had a more gradual increase in TRAQ-20 scores as age increased. By age 21, median overall TRAQ-20 scores, calculated as an average of the items for women and men, were 4.4 and 4.7, respectively.

Table 2 shows the mean domain scores for each age group for the overall cohort, males and females. The domains had different trends with respect to participant age. The “Talking with Providers” domain had a mean of > 4 for all age groups. The “Managing Daily Activities” domain had a mean of 3.2 for the 12-year-old cohort that gradually rose to a mean of 4.6. The “Managing Medications,” “Tracking Health Issues,” and “Appointment Keeping” domains had lower means in the 12-year-olds (range: 1.4 to 2.4). All of these domains had means of > 4 among the
21-year-olds. In general, females reported higher scores than males of the same age. In the “Talking with Providers” domain, males reported higher scores for the 12- and 13-year-old age groups. In the “Managing Medications” and “Appointment Keeping” domains, 21-year-old males had slightly higher scores than females (4.6 vs. 4.4 for “Managing Medications” for males and females, respectively and 4.2 vs. 4.1 for “Appointment Keeping” for males vs. females, respectively).

**DISCUSSION**

Here, we describe the trends of both the overall TRAQ-20 scores and its subdomains for a population of adolescents and young adults with IBD. Scores generally went up with age, though the trajectory for that increase varied between males and females. We also found that each of the domains had different trends with respect to age, with some domains having relatively high scores for all age groups and others showing a significant increase in score relative to age. In general, females reported higher scores than males of the same age, both for the overall score and the domain scores. Scores were similar across domains for the 21-year-olds when comparing males to females (means: “Talking with Providers” 4.6 for males vs. 4.8 for females, “Managing Daily Activities” 4.2 for males vs. 4.8 for females, “Managing Medications” 4.6 for males vs. 4.4 for females, “Tracking Health Issues” 4.4 for males vs. 4.5 for females, “Appointment Keeping” 4.2 for males vs. 4.1 for females).

Our results are consistent with and expand upon, previous studies looking at transition readiness in adolescents and young adults, which have consistently found that older patients have higher scores than younger ones and that females have higher scores than males.8,9,13,20,24–26 Figure 1 shows the centile scores for males and females over a large age range; thus, this study adds a more granular understanding of the relationship between TRAQ-20 scores and age and gender to the literature. The centile scores have a number of uses in clinical and research settings. Clinically, they allow providers to use the TRAQ-20 in the course of patient care to place a particular patient’s score in context. A provider can see that a TRAQ-20 score of 3 in a 14-year-old male is quite high in that context, but on the lower side for an 18-year-old, which can help to inform when and to whom transition support is provided during patient visits. The score distribution among the 21-year-olds in this cohort also offers some guidance as to which TRAQ-20 scores providers should expect in their patients before their transfer to adult care. Providers can also assess a patient’s progress in developing self-management skills, comparing a change in their patient’s TRAQ-20 score over time to the amount of change seen over time in this cohort, which as Figure 1 shows, varies by age and gender. In this way, this study provides something akin to normative data, making the TRAQ-20 more easily interpretable in the clinical context.

For research purposes, this study provides important data to inform how researchers decide what an adequate TRAQ-20 score is for declaring a patient as having adequate transition readiness. Previous studies have used expert-determined benchmarks for identifying adequate transition readiness.19,27 The centile scores lay out clear patterns for TRAQ-20 scores across this age range, informing future target-setting and benchmarking. They also help researchers consider age and gender, known factors associated with transition readiness when setting TRAQ-20 targets and goals. This more granular understanding of TRAQ-20 trends may also assist in understanding the relationship between TRAQ-20 scores and health outcomes by providing norms and expected scores for age groups, which can then be used in research. Further exploration of health outcomes is needed in those who do and do not achieve the score expected for their age and gender. Future evaluations of transition education and support can also be more targeted due to these curves. Transition support can be based on the skills that adolescents and young adults naturally achieve at a certain age.

The centile curves have a noticeable steep increase starting around age 17 in males. It is important to note that these data do not allow us to determine the cause for this increase. It is possible that the score represents a point at
which circumstances of life require an adolescent to learn transition readiness skills or knowledge that they had previously ignored. It is also possible that adolescents are not developmentally ready to reach that level of skill and knowledge until around the age of 17. Future work is needed to determine which factor or factors may be at work to explain this observed phenomenon.

Similar work to ours has been done with other transition readiness measures. Stollon et al20 and Zhong et al25 both evaluated associations between age and the TRAAN-SITION Index, which unlike self-report, assesses transition readiness by verifying patient knowledge and skills against the medical record rather than self-report. Stollon and colleagues examined the mean score across age groups, and Zhong and colleagues assessed the age at which patients achieved mastery of each domain, defined as a score of 75% on the domain. Stollon and colleagues specifically looked at those with IBD.

This study has several limitations. First, the IBD Partners cohorts consist of volunteers. As such, they may not represent the IBD population generally. In addition, as a way to reduce respondent burden, we did not ask about any transition preparation that participants had completed or about whether participants had transferred to adult care or not. As such, we cannot account for how those factors may have affected the observed trajectories. We relied on a self-report of IBD diagnosis for inclusion in the cohort. However, previous work has shown that the self-reported diagnosis is accurate in the larger cohort.22 In addition, all of the patients in this cohort have IBD, which may limit generalizability to adolescents and young adults with other chronic conditions. Patients were predominantly white, which limits generalizability in other races. Future work is needed to determine if trends in other populations are similar.

Using the IBD Partners cohorts, we were able to describe the trends in TRAQ-20 scores among males and females ages 12 to 21 with IBD. We found that scores generally go up with age and that males and females have different trajectories to their change in scores over time. The TRAQ-20 domains have varying trends with respect to age as well, with the “Talking with Providers” domain having high scores throughout the study age range, and others, such as “Managing Medications” and “Appointment Keeping,” moving from low to high scores as age increased. This more detailed description of the TRAQ-20 results with respect to age and gender may serve as a guide for the use of this tool in both clinical and research contexts. Just as growth curves help identify patients who are not achieving expected growth for age or not progressing as expected, these curves can help providers identify patients who are lagging with respect to transition readiness or not achieving expected increases in transition readiness scores and target supports appropriately. Having scores for a young adult population also allows for clinicians and researchers to set norm-based rather than expert-determined benchmarks for adequate transition readiness for use in studies and in determining timing of the transfer to adult care.

REFERENCES


